

Introduction

This booklet has been written by parents of children with a disability

We are a unique and diverse group of people with a wide variety of experiences and knowledge.

As parents of children with a disability, we share a common bond. We also face many challenges.

We have written this booklet to help you and your family by:

- Sharing information about other parents' experiences, ideas and suggestions
- Giving you links to information about services and support

By sharing information and supporting each other, we not only help our own family but others as well.

When we draw on our strengths as parents, we grow stronger together.



"I have been surprised to discover how many families of children with a disability there are in my local community."

Diagnosis



“That consultation when my son was officially given his diagnosis seemed to be happening in slow motion, like in a movie. I walked out of the room in a daze and then when I got to the car, I burst into tears.”

Parent and family experiences of identifying a child’s disability vary greatly

Some conditions are evident at birth or soon after. Others can occur as the result of an accident or illness.

Identifying a child’s disability and getting a diagnosis is often a gradual process that occurs over many months or years.

For some children, a clear diagnosis of a specific condition or disability (or multiple disabilities) is possible.

For others, the diagnosis of a specific condition may not be possible, or may depend on tests and observations in future years.

Mixed emotions

The process of getting a diagnosis is often a traumatic and stressful time. It can be very emotionally challenging for parents and other family members.

You may experience: fear, confusion, isolation, loss, grief, hope, shame, anger, blame, despair, exhaustion, relief, love, protectiveness and more.

You’re not alone

The range and depth of emotions we experience is often difficult for us, and those close to us, to understand.

Please remember that you are not alone. Other parents and support services are available to help you and your family during the difficult times.

Roller-coaster of emotions

The emotional ups and downs we experience are often difficult for others to understand

For many of us, our emotions are never far from the surface, especially when we find ourselves in a situation that accentuates our child's differences.

We all cope and respond differently to the challenges we face. There is no right or wrong way. Every child and every family situation is different.

Being able to discuss problems, experiences and feelings with other people who understand can be beneficial.

Some parents find it helpful to write down their thoughts, feelings and emotions. Others like to get involved in practical activities.

Seek support if you need to

The different ways in which people respond can sometimes cause tension between partners, other family members and friends. Seeking advice and support at this time can benefit all family members.

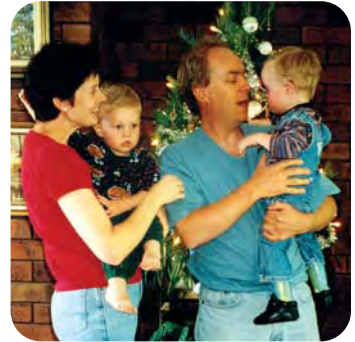
Sometimes it can be as simple as understanding the different ways that women and men tend to approach difficult issues.

Celebrate achievements

It is also important to celebrate and appreciate your child's achievements and successes, no matter how big or small.

With all the strong emotions that come with having a child with a disability, it can sometimes be hard to maintain a positive outlook.

Despite all the challenges, you and your family can still experience plenty of joy and happiness.



"From day one it has been a real roller-coaster of emotions. We try to enjoy the ups when they come and ride through the downs as best we can."

Family and friends



“I think family and friends wanted to help us, they just didn’t understand the sort of help we needed from them. Looking back now, I wish I could have found a simple way of letting them know.”

Disability can challenge our family and friends

For some of us, family and friends may have been a great source of support from day one, asking what they can do and offering practical help and understanding.

For others, friends may have drifted away and family members become more distant.

Within your extended network of family and friends, you will soon discover who is able to support you during the stressful times.

Keep in mind that it may not be easy for family and friends to understand your situation. They could be so overwhelmed that they just don’t know what to say or do.

Little things can make a big difference

Sometimes people don’t realise that there are little things they can say or do to help, or they may not know enough about your situation to understand the support you need.

Admitting to yourself and others that you need help is not always easy to do. Try to be specific about the things they could do to help.

New friendships

Don’t be afraid to let those close to you know how you are feeling. Open communication with close family and friends can sometimes lead to relationships becoming closer.

Having a child with a disability can also open the door to new friendships and support networks.

Siblings

Brothers and sisters of a child with a disability face some unique challenges

Sibling experiences and viewpoints are different from ours as parents.

A sibling's level of understanding of their brother or sister's disability will change as they grow and develop through childhood.

For example, it is common for a young child to think that they may have done something to cause their sibling's disability. As adults, it can be hard to imagine how a child could make such a connection.

Finding the right words

Finding the right words to explain a child's disability to another child can be difficult. Depending on the sibling's age and stage of development, consider their capacity to understand the issues and their ability to express themselves.

As children get older, they tend to ask more questions and seek more detailed explanations. Some questions may not have easy answers!

Open communication

Having good open communication can contribute significantly to a sibling's well-being.

Siblings need to know that you are available to answer questions about any aspect of their brother or sister's disability. They may also benefit from talking to an adult outside the family.

Siblings may find it helpful to connect with other siblings over the internet or in a sibling group, where they can share their thoughts, feelings and experiences.



"Life is different when you have a brother or sister with a disability because the experiences you go through in life, good or bad, are very different from those of other kids."

Looking after yourself



"I used to feel guilty about this thing they called respite but I don't anymore. It gives me time to relax and recharge my energy levels. I look forward to it now as a positive thing for everybody."

Looking after yourself can mean many different things

With all the other demands and responsibilities in life, parents often tend to put themselves at the bottom of the list.

Amongst all the hospital visits, specialist appointments, therapy sessions and everything else you are involved with for your child, you also need to make sure that you don't forget to think about your own needs.

It could mean finding time to be with friends or your partner, spending some quality time with your other children, enjoying a hobby, or doing some voluntary or paid work.

Because you're worth it

Looking after yourself can sometimes seem like an impossible task and involve a lot of planning and organisation, but the benefits are worth it in the long run.

Taking regular time out for yourself is good for your own health and well-being.

By looking after yourself, you will be better able to look after your child and family.